Author’s response to reviews

Title: An exploration of the conceptual understanding of Pediatric Palliative Care: A health care providers' perspective in Switzerland.

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Author’s response to reviews:

Authors’ answers to reviewer 2

The authors would sincerely like to thank the reviewer for all the time and effort invested in critically reviewing our manuscript. The thoughtful comments and generous suggestions have helped us in strengthening the manuscript considerably. We believe we have addressed all of the reviewer’s concerns. Changes in the text are highlighted in yellow.

REQUESTED REVISION 1:

The premise of this study is that "Studies exploring barriers to palliative care have focused especially on palliative care in adult health care. Fewer studies have focused on barriers to palliative care in pediatrics." Is this correct? I have written a paper on the subject, and there are many children's hospices. This may be the case in Switzerland, but is it worldwide? For this reason, Switzerland should be in the title, e.g., An exploration of the conceptual understanding of Pediatric Palliative Care: Health care providers' perspectives in Switzerland.

Authors’ response:

We sincerely thank the reviewer for asking us to clarify this point. We acknowledge that studies regarding the barriers to palliative care have been done both within the adult and pediatric
setting, but wanted to indicate that studies in adult health care tend to be more common given that the group of adult patients with PC needs is bigger compared to the pediatric patient group. We have softened the statement and we make reference to a recent review of Haines and colleagues (2018) on PPC barriers in pediatric oncology to support the claim. We also acknowledge that compared to the UK, in Switzerland awareness of children’s unique PPC needs is scant compared to other countries like the UK. We agree with the suggestion of the reviewer to add “in Switzerland” to the title.

Following the reviewer’s suggestion, the text now reads:

p. 1, line 3 and p. 3, line 54: title change: An exploration of the conceptual understanding of Pediatric Palliative Care. A health care providers’ perspective in Switzerland

p. 4, line 83-87: Studies exploring barriers to PC have focused mainly on PC in adult healthcare. Given that the group of pediatric patients with PC needs is considerably smaller compared to the adult patient group, fewer studies, with some noteworthy exceptions, have focused on barriers to PC in pediatrics and evidence specific for pediatric oncology is rather limited.

p.4, line 101-4: In Switzerland awareness of children’s unique PPC needs is scant compared to other countries like the UK.

REQUESTED REVISION 2:

The statement - "As a result, many children do not benefit from pediatric palliative care (PPC) or at least not in a timely manner" - the same could also be argued for adult palliative care.

Authors’ response:

We fully agree with the reviewer. We have made the necessary changes in the text

p. 3-4, line 78-80: Despite these recommendations, patterns of late referral continue to persist in pediatric oncology. As a result, many children – like many adult patients – do not benefit from pediatric palliative care (PPC) or at least not in a timely manner.

REQUESTED REVISION 3:

Methods - "This study is part of a larger project on end-of-life decision-making in pediatric oncology" - have the other studies been published?

Authors’ response:

We thank the reviewer for asking us to clarify this point. Yes other studies on the larger project have been published. We did not include them in the manuscript for reasons of peer-review. The
reviewer can find the references here below (for the moment in the text we left “blinded for peer-review”)

For publications regarding:


REQUESTED REVISION 4:

"Oral informed consent was sought from all participants prior to the start of the focus group." Is it not usual to provide a written information sheet and have written consent for such a study?

Authors’ response:

We thank the reviewer for the comment concerning our informed consent procedure. Since all the focus group discussions took place with professional healthcare experts, who only had a limited time for study participation and because our study had no risk to their health and well-being, we preferred oral over written informed consent. This however does not mean that the informed consent procedure was not respected. To make sure that our experts were clearly informed, we did the following:

a) We sent a letter with information on the study, the voluntary nature of their participation to each focus group participant before the actual group discussion

b) We reiterated the content and the aim of the study before the start of the focus group

c) We registered the oral informed consent of each participant

d) Transcripts were returned to participants for revision
REQUESTED REVISION 5: ADDITIONAL REQUESTS/SUGGESTIONS:

The paper concentrates on the term palliative care. Is it possible to add a sentence or short paragraph that includes details about end-of-life care, as some authors are using this phrase instead, synonymously or overlapping with? This is of interest, as another synonym might be of use. Although, given the arguments in the paper, this might not overcome initial barriers and could also have negative connotations. Is this a phrase used in Switzerland and French / German literature? Should reference be made in the literature review to such journals that are not in English as they might provide further insights?

Authors’ response:

We thank the reviewer for this important suggestion. We added a short paragraph on the relation between the terms palliative care, hospice care, terminal or end-of-life care. We also added a sentence on the lay understanding of the concept of palliative care in Switzerland. We added a reference to a (German) study on 2 surveys among the Swiss population regarding the notion of palliative care which was published in a non-English journal (Ruch C. Wer ist eigentlich Palliative Care? Palliative Ch. 2013;2:45–47). According to the survey palliative care is still relatively unknown in Switzerland but those who are familiar with it associate it with a kind of care that allows the best possible quality of life when facing an incurable illness. As shown by our results and discussion section, the healthcare professionals who participated to our study did not limit palliative care to end-of-life or terminal care, but nevertheless associated it with a non-curative phase. Furthermore (as shown by the results) participants often used synonyms such as supportive care, comfort care or “accompagnement” (see also the article of Gaille & Horn in the reference list).

Following the reviewer’s suggestion, the text now reads:

p. 3, line 57-63: For almost two decades the term has been used interchangeably with hospice, end-of-life or terminal care. In 1990 the World Health Organization (WHO) shifted away from the “end-of-life” mind-set by stating that palliative care is applicable earlier in the course of illness, in conjunction with anticancer treatment. This definition was further amended in 2002 when PC was uncoupled from prognosis and the target population was broadened to include patients facing a life-threatening condition.

p. 4-5, lines 102-104: In Switzerland the knowledge gap regarding palliative care among lay people is still great and awareness of children’s unique PPC needs is scant compared to other countries like the UK. Those who are familiar with the notion of palliative care associate it with a type of care that focuses on quality of life when faced with an incurable illness.

p.9, line 221-224 (highlighted – not new): Most providers insisted on the fact that PPC is not the same as end-of-life care or care provided when death is imminent. However, at the same time the majority of the participants insisted on the fact that within the Swiss oncology context, it is best to provide PC when there is no response to curative treatment.
Several healthcare providers suggested rebranding PPC by using a synonym which is more easily understood and less stigmatized, such as comfort care, best supportive care or “accompagnement” as these words do not directly relate to death and dying.

The interesting finding is that although they clearly distinguished PPC from end-of-life or terminal care, many of them – across the various provider types – insisted that, within the pediatric oncology context, PPC is best provided when curative treatment is no longer an option.

Added references


